

Feedback report from the CIHR Chair
in ASD Treatment and Care Research

January 29, 2013

1st Annual Chair Stakeholder Advisory Meeting

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in ASD Treatment and Care Research

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Content covered in this report

What was covered in the morning presentations?

What emerged from the afternoon group discussions?

What was the feedback like from participants?

In closing - What are the next steps?

On January 29, 2013

Dr. Jonathan Weiss, the Canadian Institutes of Health Research Chair in Autism Spectrum Disorders (ASD) Treatment and Care Research*, hosted the first Chair Stakeholder Advisory Meeting. Fifty members of the ASD community from across Canada attended, from 34 organizations. This included representatives from non-profit organizations, service providers, and government agencies, as well as researchers, self-advocates, and parents of individuals with ASD (see page 5 for the list of organizations). The primary objective of this meeting was to facilitate dialogue within the community of stakeholders and inform the Chair's research directions over the next five years. For more information on the Chair in ASD Treatment and Care Research, please visit asdmentalhealth.ca.



Dr. Jonathan Weiss

Canadian Institutes of Health Research Chair in Autism Spectrum Disorders (ASD) Treatment and Care Research

What was covered in the morning presentations?

In the morning, we heard from our keynote speaker, Dr. Debra Pepler (York University, Distinguished Researcher), on “Bullying Prevention for Children with ASD.” She talked about how children with ASD are over twice as likely to be bullied as children without ASD. Dr. Pepler emphasized the importance of context and relationships when considering bullying, prevention, and intervention. For example, peers are present 85 percent of the time when



bullying occurs, and when they intervene, bullying stops within 10 seconds most of the time. She stressed how we need to work together to foster safe and healthy relationships for people with ASD, and how this is critical both in and out of school.

Dr. Jonathan Weiss (York University) spoke about “Emergency Services, Hospitalizations, and Mental Health Care for Adolescents and Adults with ASD.” He presented preliminary findings from an ongoing CIHR-funded study, led by Dr. Yona Lunsky (Centre for Addiction and Mental Health), which is following adolescents and adults with ASD over one year, to determine the factors that lead to health care service use and emergency services. Difficulty using emergency services such as the hospital emergency room or police, appears to be related to having complex needs, such as mental

health problems and aggressive behaviours. People with ASD also experience barriers to accessing these services, such as not knowing where to find help, and feeling overwhelmed by the process of accessing services. Dr. Weiss stressed the importance of understanding mental health in the context of an individual with ASD, their families, and the larger health and social service system.

Dr. David Nicholas (University of Calgary) reviewed his findings on “Examining Maternal Care for Young Persons with Autism.” Dr. Nicholas interviewed many parents of individuals with ASD about their caregiving experiences, and spoke of challenges of access



community support, especially social support, when there are signs of difference or disability, and that a person’s assessment may not translate into active solutions in the community. Videos of all three presentations are available via online streaming at www.youtube.com/user/asdmentalhealth.

What emerged from the afternoon group discussions?

In the afternoon, stakeholders engaged in group discussions to answer three questions on how to study mental health in people with ASD and how to translate ASD mental health research to inform policy and practice. Participants were asked “What are the priority research areas with regard to the treatment and care of mental health of those with ASD and their families?”, nominated ideas, and then voted on the top 3 that they thought were most relevant. The most frequently endorsed ideas were:

- Studying the impact of mental health on the person with ASD and symptoms of ASD, and how symptoms of ASD impact mental health
- Studying factors that increase the risk of mental health problems in people with ASD
- Evaluating the effectiveness of community interventions and quantifying impacts, through partnerships with service providers
- Identifying and developing best practices for the treatment and care of mental health in people with ASD (e.g., Cognitive-Behavioural Therapy, Mindfulness)

Participants were also asked about how the Chair could best engage people with ASD, their families, service providers and decision makers in various levels of government to help involve them in the research process. The group put forward the following suggestions:

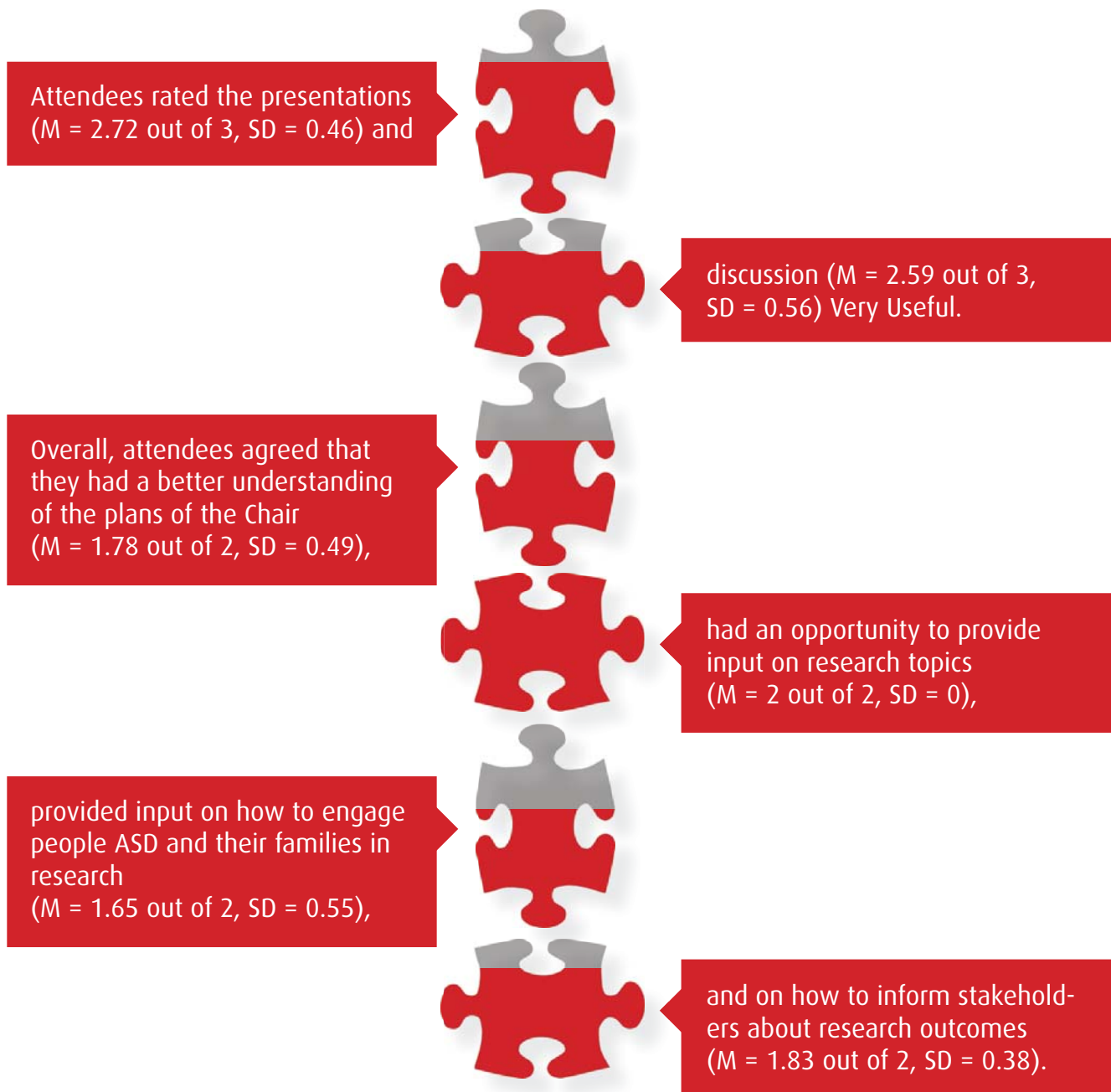
- Foster collaboration amongst Autism organizations and community agencies to establish a national voice and serve as a source of information
- Use media (e.g., TV, radio, newspapers) to increase public awareness
- Create a national registry of research
- Use social media (e.g., Facebook, YouTube, Twitter, blogs)
- Work with service providers, schools, and community organizations to disseminate information (e.g., flyers)
- Use technology (e.g., emails, newsletters, webinars)
- Put families first:
 - Emphasize the benefits of research
 - Identify barriers to participation (e.g., cost, transportation)
 - Send results of studies
 - Give families a sense of pride for participating

Finally, participants were asked about the ways in which they wanted to learn about research outcomes. They recommended the use of:

- Innovative multimedia (e.g., storytelling, pictures, sharing participants’ viewpoints)
- Plain language summaries with simpler charts and figures
- Media (e.g., newspapers, TV, magazines, TTC ads) and social media (e.g., YouTube, Facebook)
- Online forums, websites, webinars, and newsletters
- In-person presentations with Q&A periods

What was the feedback like from participants?

At the end of the day, we asked attendees to submit Feedback Forms to help us improve for our next meeting. Overall, the day was a tremendous success. Based on the 32 submitted forms, we learned that attendees most enjoyed networking with a wide range of individuals in the ASD community, the presentations, and the group discussion time. The main areas for improvement included focusing the scope of the discussion questions more and improving the location of the event.



We will surely take this feedback into consideration when planning our next Stakeholder Advisory Meeting.



In closing - What are the next steps?

This stakeholder event was the first of many opportunities to engage with the Chair in a meaningful way to inform how research can address treatment and care of people with ASD and their families in Canada. We are actively developing research projects to focus on the priority areas described above, including collaborations with service providers, and look forward to updating you on our progress over the next few months. We have also launched a specific blog: the ASD Mental Health Blog, to assist in engaging stakeholders and mobilizing knowledge about research, which will include research summaries of our articles, reviewed and edited by stakeholders prior to being posted.

A sincere thanks to all those who attended our first ASD Stakeholder Advisory Meeting. We hope it was an informative and enjoyable day, and that the chance to network and provide input on ASD research was as worthwhile a day for you as it was for us. A special thanks to our presenters on the day, Drs. Pepler and Nicholas, to Deborah Pugh from Autism Community Treatment in Vancouver, BC, for providing our closing address, and to Neil Walker for facilitating the day. If you have any questions, please do not hesitate to email Victoria Ting at vting@yorku.ca.

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